

Prostate Cancer in North Dakota

NDCR Research Series #1: A Special Report from the North Dakota Cancer Registry

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Introduction

During its first year of operation, the reporting of newly diagnosed prostate cancers to the North Dakota Cancer Registry (NDCR) was less than expected by national estimates (see table below). Although much of this can be explained by the "newness" of the state's central cancer registry operation, more mature state cancer registries are experiencing a similar experience, collecting fewer-than-expected newly diagnosed prostate cancers.

Cancer	% of Expected New Diagnoses	% of Expected Deaths
All Cancers Combined	96.8%	97.9%
Prostate Cancer	65.8%	64.7%

Source: Cancer Incidence and Mortality in North Dakota - Annual Report November 1999: Technical Notes pg. 44

The NDCR receives approximately 90 percent of all diagnosed cancers from hospital facilities; however, diagnosis and treatment plans for prostate cancers are likely to occur outside the hospital (i.e., within the physician's office).

Clinical prostate cancer screening and treatment plans may affect the reporting of prostate cancer data from the clinical facility to the state cancer registry. The screening tests (PSA with digital-rectal examination) and "watchful waiting" treatment plans may result in under reporting.

Additionally, clinical screening guidelines for the detection of prostate cancers currently are being debated for several reasons, two of which are the PSA test's false-positive rate and the benefits of early detection given treatment side effects (i.e., impotence and urinary incontinence).

The state's cancer registry does not currently have a mechanism for the reporting of cancer directly from physician offices. However, the cancer registry does collect pathology reports (of cancer-related specimens) from the major pathology laboratories in the state. Cancer diagnoses identified through a pathology report only are then followed back to the physician in order to obtain complete information. This "pathology follow-back" mechanism was established as a method of collecting the remaining 10 percent of expected cancer diagnoses each year with the goal of minimizing duplicate cancer reporting from physician offices and hospitals. A limitation to the cancer registry's current "pathology follow-back" mechanism is the possible use of out-of-state pathology laboratories by physicians diagnosing prostate cancers. (The cancer registry does not receive pathology reports from out-of-state pathology laboratories.)

Nationally, prostate cancer incidence and mortality data suggests disparities across racial and ethnic classifications (more specifically between white and black males). Black men have about a 60 percent higher incidence rate than white men, and black men have about a two-fold higher mortality rate than white men. ¹ The American Indian population is a sizeable non-white population in North Dakota's geographic boundary that may have different access to health care services (i.e., cancer screening). Such differences in access could explain possible disparities in prostate cancer incidence and mortality between white and American Indian populations.

Goals

The goals of this report are to ensure complete ascertainment and reporting of diagnosed prostate cancers among North Dakota's male population. This report provides an assessment of current incidence reporting and a plan to improve incidence reporting completeness, quality and timeliness of newly diagnosed prostate cancers in the state of North Dakota.

Objectives

The following objectives of this study are designed to achieve the stated goal (above):

- 1. Assess regional differences of prostate cancer reporting throughout the state.
- 2. Assess the incidence and mortality of prostate cancer in the state's American Indian population as compared to other racial and ethnic groups in the state.
- **3.** Assess current practices, in the state's medical community, with respect to prostate cancer diagnosis and screening.

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¹ Stanford JL, Stephenson RA, Coyle LM, Cerhan J, Correa R, Eley JW, Gilliland F, Hankey B, Kolonel LN, Kosary C, Ross R, Severson R, West D. *Prostate Cancer Trends* 1973-1995, SEER Program, National Cancer Institute. NIH Pub. No. 99-4543. Bethesda, MD, 1999.

- **4**. Identify the pathology laboratories used by the state's medical community (i.e., urologists) involved in the diagnosis and treatment of prostate cancer.
- 5. Develop and implement a plan for complete ascertainment and reporting of newly diagnosed prostate cancer to the state's cancer registry (NDCR).

The remainder of this report is outlined according to the above goals.

An assessment of regional differences of prostate cancer reporting throughout the state

The goal of this assessment objective is to identify areas in the state where there may be under reporting of newly diagnosed prostate cancers to the state cancer registry.

One way of identifying areas in the state where there may be potential under reporting is by comparing proportionate incidence rates of prostate cancer across geographic boundaries. A proportionate incidence rate is the share of a particular cancer (in this case prostate cancer) to all cancers. Assuming the risk for prostate cancer is constant across the state, the share (percentage) of prostate cancers in any given geographic area of the state should be similar to that of other geographic regions – all things being equal. Any variation in proportional incidence rates may then be attributed to difference in reporting.²

In computing proportionate rates, we used age-adjusted incidence rates for the numerator (prostate cancers) and the denominator (all cancers). By adjusting the rates, and subsequently the proportionate rates, for age differences across populations, we were able to eliminate age characteristics of the populations as a confounding factor in explaining any variation across the geographic boundaries.

The geographic boundaries used in this assessment are the eight (8) Regional Human Service Center regions in the state. Each of these regions is an aggregation of North Dakota county populations. (See map in Appendix II.)

Figure 1 depicts a bar graph that compares the proportionate incidence rate of prostate cancer across the eight Regional Human Service Center regions as well as for the entire state of North Dakota. The statewide proportionate incidence rate for prostate cancer is 18 percent. Put another way, 18 percent of all cancers in the state are prostate cancers. This statewide proportion also can be viewed as the statewide average proportionate rate. Prostate cancer is the most frequently reported cancer to the state cancer registry.

² Variation in proportional incidence rates across geographic boundaries also could be attributed to differences in prostate cancer screening, treatment options and population characteristics.

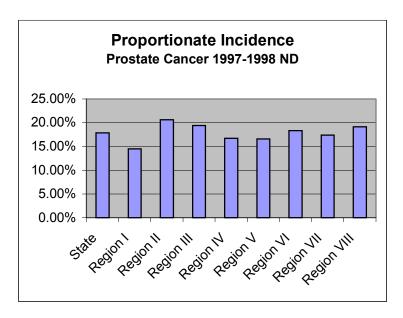


Figure 1

The bar graph in Figure 1 also shows that, for the most part, each region's proportionate incidence rate ranges between 15 percent and 20 percent. Region I shows a proportionate rate below 15 percent; however, this proportion is based on 34 observations of prostate cancers.³ None of the individual regional proportionate rates differ, statistically, from the statewide average of 18 percent. Therefore, we conclude there is no significantly different reporting across the state of North Dakota of newly diagnosed prostate cancers to the state cancer registry.

A comparison of prostate cancer incidence and mortality in the state's American Indian population compared to other racial and ethnic groups in the state

To assess differences in prostate cancer incidence and mortality across racial and ethnic populations in the state, we compared the proportionate incidence rates of specific cancers for various racial/ethnic groups. We compared three racial/ethnic groups in the state: whites (W), American Indians (AI), and other racial/ethnic groups (O).⁴ For each of these racial/ethnic groups, we compared proportionate incidence rates for the most common cancers reported to the state cancer registry: prostate, colorectal, lung and breast.⁵ The table below compares the proportionate incidence rates of these cancer types for the three-racial/ethnic groups.

³ The next largest numbers of observations for a region in this assessment was Region VIII with 75 observations of prostate cancer. Small numbers create difficulty in interpreting statistical rates and proportions.

⁴ Other racial/ethnic groups include those reported to the cancer registry as other and unknown.
⁵ A proportionate incidence rate is the proportion of a specific cancer type to all cancers for the defined population. For example, the proportionate incidence rate of prostate cancers for American Indians is the number of prostate cancers for that racial/ethnic group divided by the number of all cancers for that racial/ethnic group.

	Whites	AI	Other
Prostate	1528 (16.8%)	18 (10.5%)	13 (10.4%)
Colorectal	989 (10.9%)	16 (9.3%)	13 (10.4%)
Lung	1002 (11.1%)	36 (20.9%)	4 (3.2%)
Breast	1371 (15.1%)	24 (13.9%)	22 (17.7%)
All Cancers	9054	172	124
Table 1		•	

Data for the above table comes from data reported to the state cancer registry through November 2000 and represents complete incidence data for the first two years of incidence reporting (1997-1998) and partial data for the years of 1999 and 2000.

In the above table we see differences in the proportionate incidence between whites and American Indians for prostate cancer (16.8 percent vs. 10.5 percent respectively) and lung cancer (11.1 percent and 20.9 percent respectively). This lower proportionate incidence of prostate cancer among American Indians lends support to other findings that show the incidence of prostate cancer is lowest among American Indians. The differences in lung cancer proportionate incidence may be explained in differences in smoking rates between whites and American Indians. Interpretation of the proportionate incidence for the other racial/ethnic group is difficult since the majority (76.6 percent) of the data in this racial/ethic group is represented by unidentified race/ethnicity.

We also performed a similar comparison with respect to proportionate mortality rates. The table below compares the proportionate mortality rates of the same cancer types for the three racial/ethnic groups.

•	Whites	AI	Other
Prostate	242 (8.4%)	0 (0.0%)	0 (0.0%)
Colorectal	329 (11.4%)	11 (12.9%)	1 (8.3%)
Lung	702 (24.4%)	27 (31.8%)	5 (41.6%)
Breast	233 (8.1%)	5 (5.9%)	2 (16.6%)
All Cancers	2881	85	12
Table 2			

Data for the above table comes from the state's vital statistics mortality database and represents deaths occurring in 1997 and 1998.

In the above table we see a difference in the proportionate mortality of lung cancer between whites and American Indians (24.4 percent vs. 31.8 percent respectively). Given the relatively high case fatality rate with lung cancer, this difference is likely to be reflective of the different proportionate incidence shown in Table 2 (above). The proportionate mortality of colorectal and breast cancer between whites and American Indians is similar. There were no deaths from prostate cancer among American Indians. Interpreting the proportionate mortality of the various cancer causes of death for the other racial/ethnic group is difficult due to the small number of observations in this group (fewer than 20 observations).

Our analysis of incidence and mortality cancer data among American Indians in the state of North Dakota reveals a few things:

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⁶ A published study by the SEER program found "the lowest incidence rates [of prostate cancer] are found in Native Americans and all other groups have lower rates than whites and blacks." (see Appendix I)

- The proportionate incidence of prostate cancer is lower among American Indians compared to whites. This lends support to other studies that find prostate cancer incidence lowest among American Indians.
- The proportionate incidence and mortality of lung cancer is greater among American Indians compared to whites. This finding may be explained by different smoking rates between these two racial/ethnic groups.
- There were no deaths from prostate cancer among American Indians in 1997 and 1998. The leading cause of death for this racial/ethnic group is acute myocardial infarction (AMI).

An assessment of current practices, in the state's medical community with respect to prostate cancer diagnosis and screening

Another goal of this report was to assess current practices in the state's medical community with respect to prostate cancer diagnosis and screening. To perform this assessment, the NDCR surveyed a selected group of the state's licensed physicians. The purpose of this survey was two-fold: (1) to obtain information about the current practices of the state's physicians with respect to prostate cancer screening, and (2) to understand how physicians report newly diagnosed cancers to the state cancer registry.

Four hundred and nine (409) surveys were mailed out, and a total of 194 survey responses were received for a 47 percent response rate. The following shows the survey questions and summarizes the percentage of responses received.

Section 1 – Description of Clinical Setting

Please answer the following questions to describe the clinical setting where you work:

	What settir	ng best describes your place of work?		
		A. Private Office or Laboratory	-	9.4%
		B. Group Practice	-	71.8%
		C. Hospital	-	8.9%
		D. Other (e.g. rural health clinic,		
		walk-in clinic, residency)	-	9.9%
)	What is vo	ur alinical practice enecialty?		

2. What is your clinical practice specialty?

_	A. Oldiogy	-	1.4/0
	B. Oncology	-	5.2%
	C. Surgery		
	D. Internal Medicine		
	E. Pathology		

□ F. Other - Family Practice - 81.4%

Combination of specialties including surgery, etc.
6.2%

3. On average, how many patients do you see each month?

□ A. 1 – 50 - 6.5% □ B. 51 – 100 - 7.8% 7 20%

□ C. 101 – 500 - 76.3%
□ D. More than 500 - 9.4%

4. On average, how many patients do you see each month for a prostate cancer related condition?

A. $1 - 10$	-	76.5%
B. $11 - 20$	-	14.4%
C. 21–50	-	5.9%
D. More than 50	_	3.2%

Section 2 – Screening and Diagnostic Practices

Please answer the following questions that best describes your current screening and diagnostic practices with respect to prostate cancer detection:

5. Among your male patients that do not show increased risk factors for prostate cancer, at what age do you begin screening with a Digital Rectal Exam (DRE)?

A. Beginning at age 35	-	3.3%
B. Beginning at age 40	-	45.6%
C. Beginning at age 45	-	8.8%
D. Beginning at age 50	-	42.3%
E. Beginning at age 55	-	0.0%
F. Beginning at age 60	_	0.0%

6. Among your male patients that do not show increased risk factors for prostate cancer, at what age do you begin screening with a Prostate Specific Antigen (PSA) test?

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    □ A. Beginning at age 35
    □ B. Beginning at age 40
    □ C. Beginning at age 45
    □ D. Beginning at age 50
    □ E. Beginning at age 55
    □ E. Beginning at age 55
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7. Among your male patients that do not show increased risk factors for prostate cancer, how frequently do you screen them for prostate cancer with DRE's?

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    □ A. Once every six months
    □ B. Once a year
    □ C. Once every-other year
    □ D. Never
    □ 2.7%
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8. Among your male patients that do not show increased risk factors for prostate cancer, how frequently do you screen them for prostate cancer with PSA tests?

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    □ A. Once every six months
    □ B. Once a year
    □ C. Once every-other year
    □ D. Never
    □ 4.4%
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9. Where do you send your patient's PSA tests and/or tissue specimens for analysis? (check all that apply)

A. Outside laboratory; within North Dakota	- (37.3%
B. Outside laboratory; outside North Dakota	-	7.2%
C. In-house laboratory; within my practicing		

facility - 55.5%

D. Other (please describe) - 0.0%

10. Please provide us the name and contact information of all laboratories used by your practice for evaluating prostate cancer diagnoses and treatment surveillance:

(For a list of responses, please see the table in the next section. This table lists the names of the various pathology labs used by the respondents in this survey.)

Section 3 – Cancer Reporting Practices

Please answer the following questions that best describes your current understanding and/or knowledge:

11. When did cancer become a reportable disease as defined by ND state law and administrative rule?

□ A. 1993 - 25.6%
□ B. 1995 - 30.2%
□ C. 1997 - 21.7%
□ D. 1999 - 17.1%
□ E. 2000 - 5.4%

12. What best describes the process in which you report newly diagnosed prostate cancers to the state cancer registry?

□ A. Through ND Morbidity Report card
 □ B. Through hospital ca registry
 □ C. Through the laboratory
 □ D. Not applicable / Other
 - 2.6%
 - 47.9%
 - 12.3%
 - 36.0%

13. Do you document your patients' race and ethnic classification in their medical record?

□ A. Yes - 47.9% □ B. No - 52.1%

14. How do you determine your patients' race and ethnic classification? (among yes respondents to question 13)

□ A. Patient self identifies
 □ B. From other documentation
 □ C. Do not obtain (n/a)
 □ D. After reviewing info from medical exam

Identification of pathology laboratories used by the state's medical community involved in the diagnosis and treatment of prostate cancer

The North Dakota Cancer Registry currently receives pathology reports (of cancer-related specimens) from several major laboratories in the state. Cancer diagnoses identified through a pathology report only are then followed back to the physician in order to obtain complete information. This "pathology follow-back" mechanism was established as a method of collecting the estimated 10 percent of expected cancers

diagnosed each year with a goal of minimizing duplicate cancer reporting from physician offices and hospitals. A limitation to this current "pathology follow-back" mechanism is the possible use of out-of-state pathology laboratories by physicians diagnosing prostate cancers; currently, the cancer registry does not receive pathology reports from out-of-state pathology laboratories.

A question on the clinician survey asked each respondent to list the names of all laboratories used in their practice for evaluating prostate cancer diagnosis and treatment surveillance. The table below lists the various responses to this question.

10. Please provide us the name and contact information of all laboratories used by your practice for evaluating prostate cancer diagnoses and treatment surveillance:
Altru Clinic
Armed Forces Institute Pathology
Quain & Ramstad Clinic Lab
Carrington Health Center
Dakota Clinic
Dianon Systems
Lake Region Clinic
MAC
Mayo Lab
MCS Pathology QNC9 Pathology
MedCenter One Health Systems
Williston Mercy Medical Center
MeritCare Clinic Lab
Mid Dakota Clinic
New Brighton Lab
Pathology Consultants
Quest Diagnostics
Regional Lab Facility
Smith Kline
St. Andrew's Hospital Lab
St. Francis Medical Center
St. Joseph Hospital
Trinity Hospital Lab
UND Pathology Dept
UNDFPC Laboratories
UniMed Medical Center
West River Regional Medical Center
Wishek Community Hospital

This question was asked to help the cancer registry identify all possible laboratories used by clinicians throughout the state and to expand cancer pathology reporting from these laboratories. In addition to using in-state laboratories, clinicians also use out-of-

state laboratories. (7 percent of survey respondents use an out-of-state laboratory.) These laboratories include Dianon Systems, Smith Kline, Quest Diagnostics, Regional Lab Facility, New Brighton Lab, Mayo Lab and possibly the Armed Forces Institute of Pathology.

Development and implementation of a plan for complete ascertainment and reporting of newly diagnosed prostate cancer to the state's cancer registry (NDCR)

This section of the report outlines a plan for the state cancer registry to help achieve complete ascertainment and reporting of prostate cancers in North Dakota.

Our regional analysis of where prostate cancers are being reported across the state suggests there is no real geographical difference with respect to where prostate cancers are being reported. Given that the total number of prostate cancers reported to the state cancer registry is below estimates, this non-difference may suggest that the under-reporting of prostate cancers is distributed evenly across the state. Hence, a plan to ensure complete ascertainment and reporting of prostate cancers to the state cancer registry should be implemented statewide, rather than targeted to specific areas in the state.

Our survey's findings revealing that 12 percent of the physicians in the pathology laboratory do report newly diagnosed cancers to the state cancer registry suggest the plan should include activities to obtain more laboratory data on cancer-related specimens. Currently, the state cancer registry does not collect pathology report data from all pathology labs in the state. Our survey also discovered that 7 percent of the state's clinicians utilize out-of-state laboratories. The plan also should include efforts to obtain pathology laboratory data from these out-of-state labs.

When asked what best describes how they report newly diagnosed prostate cancers to the state cancer registry, 36 percent of the responding clinicians indicated "not-applicable" or "other." Many of these responses described various reasons:

- Didn't know I need to report cancer to the state registry.
- Refer the patient to a urologist and rely on the urologist to report the data to the state cancer registry.
- Don't have any prostate cancers patients.

Implementing a clinician-reporting process also may help obtain additional prostate cancer reports to the state cancer registry. Given that a prostate cancer diagnosis may not be reported because of the "watch-n-wait" option, a clinician-reporting process can increase the number of prostate cancer reports.

The state cancer registry's Web database application can be used to establish online cancer reporting for clinicians and pathology labs. This would provide a timely, and paperless, means for clinicians to report a brief abstract of newly diagnosed cancers. This also would provide a straightforward way for pathology labs to submit data to the state cancer registry.

To summarize, a plan to capture complete reporting of prostate cancer data to the state cancer registry should include:

- Statewide implementation with targeted implementation in future years if necessary.
- Capture of additional pathology lab data within and outside North Dakota.
- Implementation of a clinician rapid-reporting process.
- Enhancement of the registry's Web database application to provide online clinician and pathology lab reporting.

Appendix I

The following information is published on the SEER website: http://seer.cancer.gov/publications/prostate/.

Prostate Cancer Trends 1973-1995 (SEER)

Highlights and Links to Text

The SEER Program of the National Cancer Institute is pleased to release this monograph on prostate cancer in the United States from 1973 through 1995. This monograph resulted from the work of the 11 SEER registries, the SEER staff, and the editors. Since prostate cancer is the number one incident cancer and the number two cause of cancer deaths among U.S. men, the data in this monograph are important for researchers, clinicians, policy makers and citizens in understanding this disease. A few of the highlights from the monograph are listed below:

Monograph Data

Data are from the SEER program which has registries covering 14% of the U.S. population.

272,689 cases with histologically confirmed adenocarcinoma of the prostate newly diagnosed between 1973 and 1995 are included.

Mortality data are both from the SEER areas and the entire U.S. population.

Data for the 23-year period are presented for whites and blacks. Data for Asians, Native Americans, and Hispanics are only available for 1990-1995 and are presented in a separate section.

Incidence

Black men have about a 60% higher incidence rate than white men.

Incidence rates modestly increased from 1973-1986, rapidly increased from 1987-1992, and declined from 1993-1995.

Incidence rates increased 108% for white men from 1986-1992 and 102% for black men from 1986-1993; these increases in rates are believed to be related to use of the prostate-specific antigen (PSA) blood test as a new screening tool.

The increase from 1986-1992 occurred in all age groups; the median age at diagnosis decreased by one year for whites and for blacks between 1980-1985 and 1990-1995.

The increase from 1986-1992 occurred for both localized and regional stages of disease and mostly in moderately differentiated tumors.

Incidence of distant stage prostate cancer peaked in 1985 and by 1995 declined by 56%.

Mortality

Black men have about a 2-fold higher mortality rate than white men.

Death rates from prostate cancer have gradually increased over the last 20 years, but peaked in 1991 and 1993 for white and black men, respectively.

The median age of death increased between 1980-1985 and 1990-1995 by one year in both whites and blacks.

Though death rates have slightly decreased in recent years, a decline in the absolute number of deaths was first noted in 1995. In white men under age 75, the age-adjusted mortality rate declined by 15% between 1990 and 1995.

Grade and Stage

Between 1973-1995, about 60% of prostate cancers were diagnosed at a localized stage and about 40% were graded as moderately differentiated. The percent of moderately differentiated cancers differed little by race, but decreased slightly with advancing age.

Stage and grade are correlated; as the grade becomes less differentiated the stage is likely to be more advanced.

The rapid increase in prostate cancer incidence from 1986-1992 was confined to moderately differentiated cancers for all ages and for whites and blacks.

Treatment

Only treatment data for 1983-1995 are included, as these are the only years with consistent coding. The monograph focuses on treatment patterns in localized and regional stage cancers.

The increased incidence (1986-1992) was accompanied by increases in more aggressive therapy (radical prostatectomy or radiation therapy) for localized and regional cancers.

Recent treatment patterns for local/regional cancers vary by age: radical prostatectomy is more frequent among men under age 70, radiation therapy in those age 70-79, and conservative therapy (no treatment or hormonal therapy) in those over age 79.

Treatment for distant stage cancers has not changed over time with about 65% of patients receiving hormonal therapy.

Survival

Based on cases diagnosed in 1990 and followed through 1995, 93% of all men diagnosed with prostate cancer will survive five years or longer.

Relative survival rates have increased since 1973 for both black and white men, but the difference between blacks and whites has increased over time (survival has not improved as rapidly in black men).

Consistent improvements in relative survival have occurred over time (1973 to 1993) for localized and regional stage cancers, with relative five-year survival now exceeding 99%.

Relative survival has increased over time for all grades of cancer.

Relative survival for younger men (age <50) is lower than for older men.

Five-year relative survival for distant stage disease is 34% and has not improved over time.

Race/Ethnicity

The lowest incidence rates are found in Native Americans and all other groups have lower rates than whites and blacks. The incidence rates peaked in 1992 for all groups except blacks, where it peaked in 1993.

National mortality rates are not available for Asians and Native Americans; mortality rates are available for white-Hispanics, and their rates have not decreased as they have for blacks and white non-Hispanics.

Stage distribution is similar across races, except the proportion with distant stage disease is higher for Hawaiians, Filipinos, and Native Americans.

Filipino men have slightly more poorly differentiated cancers than the other groups. The proportion of tumors that are well or moderately differentiated is similar across all groups.

Of patients with localized or regional stage prostate cancer, Native Americans have the poorest relative survival of all racial/ethnic groups. Blacks and white-Hispanics have the lowest five-year relative survival rates among patients with distant stage disease.

Appendix II

